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ABSTRACT

The site visit report describes the Residential Support Program of the Centennial Developmental Services, a community-centered board providing residential services and support to persons (currently 67) with disabilities in Weld County, Colorado. Residential settings include a group home, supported apartments, foster homes, natural family homes, or independent living. The level of support offered ranges from live-in, full-time coverage, to part-time staffing, to follow-along support a few hours per week or month. The report focuses on case studies of six people supported by the program including descriptions of the physical settings and their daily routines. Key components of the program philosophy include providing residential supports to individuals in their own homes, promoting a sense of home, promoting as much independence as possible, the belief that all people with disabilities belong in the community, and promoting an alternative to a continuum-based model of services. Program strengths include the small-scale, dispersed settings; individualized placements and supports; individualized, flexible programming in natural contexts; and staff relationships with each other and the people they support. (DB)

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SITE VISIT REPORT

CENTENNIAL DEVELOPMENTAL

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Supporting People in the Community: A Case Study of the Residential Support Program, Centennial Developmental Services, Weld County, Colorado

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January 1987

This is one of a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices for integrating people with disabilities into community life.

Supporting People in the Community: A Case Study of the Residential Support Program, Centennial Developmental Services, Weld County, Colorado

Introduction

In Colorado, residential and other services for people with developmental disabilities are provided through 22 community-centered boards (CCBs), serving one or a few counties each. Some CCBs provide services themselves, while others contract with private agencies for them. In Weld County, the CCB, Centennial Developmental Services, Inc. (CDS), directly provides residential services and supports.

CDS supports 67 people with disabilities in residential settings including a group home, supported apartments, "host homes" (foster homes), and individuals living with their natural families or in their own homes and apartments. The level of support ranges from live-in, full-time coverage, to part-time staffing, to follow-along support a few hours per week or month.

In Weld County, numerous individuals with disabilities are being supported in individualized ways in the community. This case study will describe some of the ways in which these people are supported, as well as highlight some of the agency philosophies and practices that make this possible.

Setting

Weld County is a predominantly rural county located approximately 60 miles northeast of Denver. The county contains two small cities, Greeley and Evans, which are adjacent to one another. Housing is generally modest, but well-maintained, as

are the surrounding lawns and shrubbery. Recent development includes some housing subdivisions of modest scale, small-scale shopping plazas and malls, and apartment complexes on the fringes of the urban area. Greeley is home to the University of Northern Colorado, which contributes a college-town atmosphere. The landscape surrounding the Greeley-Evans area is plains environment, utilized for agricultural purposes; on the horizon, one has a picturesque view of the snow-capped Rockies, some 40 miles to the west.

Background

In the recent past, there has been an agency focus on "down-sizing" existing larger settings, dispersing apartment sites, and the development of smaller, more individualized residential supports. By August 1986, there were five people living in one group home; 40 in supported apartments, houses, or host homes; and 22 additional people receiving follow-along services. To support these 67 people, CDS employs 12 "community support specialists."

For the purposes of this case study, focus will be placed upon six people who are supported by CDS--Lisa, Susan, Mike, Tim, Sarah, and Debbie--and the staff people who assist them.

People

Lisa and Susan

Lisa and Susan share an apartment in Greeley, supported by CDS. Lisa, who is 44 years old, uses a wheelchair; Susan, who is 29, is blind. Both could probably be labeled moderately mentally

retarded. In the past, both lived at Grand Junction Regional Center, and shared a room there. In addition to a diagnosis of severe mental retardation, according to a staff member of CDS, Lisa was considered to have "social-emotional" problems, while Susan had a diagnosis of schizophrenia and a history of self-abusive behaviors.

In the summer of 1985, Jay Klein, the Director of the Residential Support program in Weld County proposed to the state that CDS would take 8 people from Pueblo Regional Center and 2 people from the community--no matter how severe their disabilities--and support them in the community, at a rate of $92.50 per person per day. The state told him the agency could take three people at $43.00 per day from Grand Junction Regional Center. This arrangement was agreed upon in August and CDS targeted October 1 as the date for implementation. Lisa and Susan were selected as two of the people to move from Grand Junction. They moved to their present apartment in October 1985.

The two-bedroom apartment is located in a multi-unit apartment complex on the outskirts of the city. Nearby are some single family residences, a small shopping plaza, and open fields. To the west, in the distance, there is a view of the mountains.

Each building contains three floors, with eight apartments each; the basement level apartments in one building are wheelchair accessible, and this is where Lisa and Susan reside.

As one enters the apartment, there is a large open space which is used as dining room area, living room, and kitchen. A somewhat worn couch and chair create a division in space between

the living area and kitchen area. In the corner of the living room area is a large television set and a videocassette recorder. A plant hangs in the window. The dining area contains a medium-size table, lamp, telephone stand, and a small table with a microwave oven on it. On the wall over the table is posted the two-page emergency procedures established by CDS for Lisa and Susan. The kitchen is equipped with ample cabinet space, double sink, stove, dishwasher, and a refrigerator/freezer. None of this space is specifically wheelchair accessible, although from her wheelchair Lisa can perform numerous activities in this area, such as use of the two front burners of the stove, the dishwasher, and getting items out of the refrigerator. Many household items are stored in lower cabinets so Lisa can reach them.

Lisa's room is painted white with sheer off-white curtains. Attractive touches are added by a multi-colored Mexican blanket on the bed and a ceramic mobile hanging in the window. Next to the bed is a small stand with a telephone on top. Although Lisa sometimes writes letters, she said she keeps in touch with friends and relatives primarily through telephone calls. This phone is equipped with a speed dialing mechanism for emergencies. There are two dressers with numerous personal possessions on each. In between the two, in the corner, a stereo system sits atop a box.

Susan's room, next to Lisa's, is also painted white, with sheer off-white curtains. The bed has a half-made look. The walls are bare. Along one wall is a dresser, which has a few items on top, one of which is a bowling trophy. Susan told me

that she doesn't bowl anymore, but that she used to frequently when she lived in Grand Junction. On the floor is a case with some records and tapes.

Throughout the apartment there seems to be a need for some additional furniture, particularly smaller tables for use in the living room as end tables, and in the bedrooms on which to keep personal possessions. In addition, some of the furnishings appear to be somewhat worn. However, this is balanced by attractive and enhancing additions, such as the hanging plant, the microwave, and the television and VCR. Overall, the apartment is well-maintained, bright, and attractive, and appears to be a pleasant place to live.

The emergency procedures posted on the wall provide the visitor with the most obvious clue that this is not just an ordinary apartment shared by two women, but is part of an agency or program. Further, a note on the refrigerator door regarding Susan's need for assistance with personal hygiene detracts from the otherwise quite enhancing image of Lisa and Susan that is presented by this apartment.

A final observation about this apartment is the contrast that is present between Lisa and Susan's bedrooms and personal possessions. Although some of the items in Lisa's room could be considered not age-appropriate (such as the cabbage-patch type doll on her bed or a stuffed spider in the corner), the overall appearance of her living environment is one that is colorful as well as filled with personalized possessions. Many of these are gifts from her sister and brother-in-law; and such a presence of gifts from others seems to signify the presence of others in

one's life who care. In contrast, Susan's room is relatively bare and unadorned--presenting the image of one who does not have as many social connections or relationships.

Since the time of the site visit, a number of changes have taken place. Lisa's sister bought living room furniture for the apartment, staff have assisted Susan in adding a greater degree of personalization to her bedroom, and the emergency procedures and other staff notes are no longer posted on the walls or the refrigerator door.

Daily life. During the weekdays, Lisa and Susan get up at about 7:00. A visiting nurse from a local agency comes to assist Lisa with washing and dressing from 7:00-7:30. Then Lisa and Susan work together to prepare their breakfast, with Lisa sometimes cooking herself and sometimes directing Susan if needed as she performs certain tasks. Lisa is becoming increasingly adept at using the microwave, and for breakfast might cook microwave eggs or hot cereal. After breakfast, both utilize a specialized, wheelchair-accessible bus service for transportation to the Vocational Center, where they work from about 9:00 to 2:30. (The city bus, which is wheelchair accessible, will pick people up at their door if they call ahead to arrange it, although not as a regular, daily service.)

The Vocational Center, run by the CCB, is located in a former elementary school next door to the Centennial Developmental Services offices. There are about 14 people with developmental disabilities who work at the Vocational Center itself, and about another 16 or so who work on work crews out of the Center. For those people who work at the Vocational Center,

most of their day is spent sorting objects by shape and/or color. When asked what happened after she was finished with her current task, one worker responded, "I don't know, I guess they mix them all together again." The Vocational Center does not pay the people who work here. It is considered to be "higher on the continuum of vocational services" than the local sheltered workshop, Schafer, since it is supposedly the stepping stone to community-based employment opportunities, such as the work crews, enclaves, or competitive supported employment.

Schafer employs about 120 people with disabilities, paying them at least a nominal wage for their labor. Work here seems to be more meaningful than that at the Vocational Center, since it consists of "real jobs" (e.g., assembling videotape boxes for Kodak), rather than work that will later be "undone." There is the possibility for placement out of the workshop into community work sites, although I was told that movement in the past few months had been quite minimal. In turn, waiting lists to work at Schafer are growing. With the assistance of her case manager, Lisa has toured Schafer and placed her name on the waiting list. (She is also on the waiting list for community-based placement out of the Vocational Center, and would take which ever opportunity arose first.) When asked why she wanted to work at Schafer, Lisa replied "for the money " and "to work with more friends."

Lisa and Susan arrive home in the afternoon at about 3:00 or so. They are met there by a staff person, who stays until about 8:00 in the evening. On the day I visited, this person was Marcia, who is 24 years old. She has been working for CDS since

May 1986. Prior to that, she was employed in the field of physical therapy. In addition to this job, she still maintains a position as a personal care attendant for a woman with physical disabilities. In addition, other support staff may come to the apartment during the week or weekend to spend time or go out with Lisa or Susan.

In addition to the staff people who come to the apartment on weekdays and on weekends (from about 7:30 am to 7:00 pm), Lisa and Susan each have a "primary community support specialist" staff person as well as a "back-up community support specialist." The primary support person spends about three hours per week with them--although this number of hours and the way it is distributed throughout the week is flexible. The back-up person might come to visit once every two or three weeks for an hour or so.

When they come home from work, Marcia explained that Lisa and Susan "typically like to unwind for awhile." Lisa said she likes to watch TV or listen to her radio. Susan, on the other hand, likes to sit on the couch in the living room and listen to the TV, or talk to whomever is around. When the weather is nice, Lisa also particularly enjoys going out to sit in the courtyard adjacent to the apartment.

Later in the afternoon, Susan usually either goes for a walk or goes swimming with her friend, Debbie (who also has disabilities and is supported by CDS). I accompanied Susan, Debbie, and Marcia as they went swimming together. Both Susan and Marcia displayed obvious pride as they demonstrated for me Susan's newly mastered ability to independently swim the width of

the pool, with Marcia calling to her if needed to keep her headed in the right direction. On occasion, Lisa goes swimming too. Once a week, a staff member, Jan, comes to assist Lisa with money management skills. At other times, Jan comes just to have a social visit with Lisa. Lisa had requested this, and Jan changed her schedule to accommodate the request. Similarly, at least once a week, a staff member comes to spend time with Susan and work on skill development. Also, once a week a person from the local Association for the Blind comes to work with Susan--they are working on braille typing, and are planning on putting together a braille cookbook in the near future.

With the assistance of the staff person, Lisa and Susan work together to prepare dinner. On this particular day, Lisa and Marcia use a wok to prepare a Chinese stir fry. In the meantime, Susan unloads the dishwasher, puts away the clean dishes, and sets the table. When asked what she thinks about all the work that goes into living in an apartment situation such as this, her response is, "I like it. It doesn't bother me."

Then, Lisa, Susan, and Marcia sit down to dinner. Sometimes Debbie stays for dinner; other times she does not. On occasion, someone else may drop by for dinner, or for tea or coffee afterwards, such as another CDS staff person who is not working at the time.

After dinner, Lisa and Marcia clear the table and load the dishwasher. Susan makes lunches for herself and Lisa for the next day's work. After this is done, Susan usually takes a

shower and gets ready for bed. A visiting nurse comes again in the evening--from 8:00 to 9:00 pm--to assist Lisa in preparing for bed.

On weekends, the schedule and activities vary. The visiting nurse comes about an hour later to assist Lisa. There may be some household chores to do--Susan is gaining proficiency at cleaning the bathroom; both Lisa and Susan use the vacuum cleaner in the common rooms and their bedrooms. On Saturday evenings, Lisa goes to church with her friends Sarah and Ted (two other individuals who are supported by CDS; Lisa and Sarah knew one another at Grand Junction Regional Center); after church the three of them go to visit some other friends who are living in supported living situations in Greeley. Other weekend activities might include spontaneously going out for dinner with one of the support staff people; going to a play; going shopping; taking a drive to the mountains; going to a party; and so forth. During my visit, Lisa recalled a recent trip to the mountains, adding, "I love the mountains." In addition, she mentioned that she was looking forward to attending a 25th wedding anniversary party for Marcia's parents.

Although Lisa and Susan have a lot of social contacts, and participate in numerous activities in community settings, most of this is either with CDS staff and/or other people with disabilities; relationships with nondisabled people who are not staff are more limited, although staff at CDS are working to help increase such contact. For instance, with staff assistance, Lisa and Susan have gotten to know some people on their apartment floor, particularly Betty, the apartment manager, and her husband

Don, with whom they exchange conversation in the hallway or drop in to visit from time to time. Betty is willing to be a back-up emergency contact person when staff are not at the apartment. In addition, two other women who share an apartment on this floor are also willing to be contacted in case of emergency. In this way, the agency is helping to develop networks of support for Lisa and Susan that involve their neighbors.

Susan has some contact with her mother and her grandmother. She has a closer relationship with her grandmother than her mother, and had lived with this grandmother prior to living in Grand Junction. She maintains frequent contact with her grandmother by telephone, and occasionally visits her mother in Denver. Lisa also has some contact with her mother, but not a close relationship. She is more regularly in touch with her sister and brother-in-law. She tells, in what to me is a very moving story, about how her sister objected to her moving out of Grand Junction into this apartment. Yet, Lisa was able to make the move despite the strong disapproval from her sister, saying to her sister, "I'm going to move; it's something I have to do for myself." Since Lisa has been here, her sister has come to visit three times, and, according to Marcia, is beginning to feel better about this living arrangement.

Finally, for her vacation this summer Lisa decided she wanted to go back and spend a week visiting friends at Grand Junction Regional Center. While there, she stayed at one of the "satellite" homes on the grounds of the institution. In retrospect, she indicated that the visit had been difficult for her, with staff telling her what time she had to go to bed,

taking control of her medications, and so forth. After almost a year of beginning to make many of her own choices and take control over many areas of her life, this type of staff control was difficult for her to accept.

Overall, Lisa and Susan seem to be a "good match" for apartment sharing. They have a close, supportive friendship, and are able to combine their strengths and abilities to work together to achieve increasing independence and interdependence. On rare occasions, Susan, whose past history is characterized by significant self-abuse, still begins to use self-abusive behaviors such as lightly slapping her face, scratching herself, and biting her wrist. However, at these times, Lisa can redirect her with a gentle reminder, in a manner that in quite unobtrusive--a relationship that is able to accomplish what years of "behavior modification" could not.

Mike and Tim

On June 15, Mike and Tim moved into a small house in a quiet residential neighborhood in Greeley. Mike, who is 33, could probably be characterized as moderately mentally retarded; Tim, who is 31, could probably be described as mildly disabled. Matt, a young man of 22, who is employed by CDS as a live-in staff support person, resides in a basement apartment in this house. In addition, Mike and Tim each have a "primary" and a "back-up" staff support person provided by CDS. Gwen, who is in her late 20's and has been with the agency for about a year, is the primary support person for Mike. Joe, perhaps in his late 30's, has been employed by CDS for about six months and is the primary

support person for Tim. Gail, a CDS staff member who lives with her husband and children almost directly across the street from this new home, provides back-up support.

Both Mike and Tim formerly lived in a group home (of eight men) located about a half mile from this house. In addition to the agency desire to "downsize" this group home, Mike, who has only limited verbal ability, seemed to be unhappy, and was expressing this through aggressive outbursts of anger.

In order to help determine what kind of living arrangement would be good for Mike, CDS organized a "life planning meeting." At this meeting, 19 people who knew Mike came together with each other and him to share ideas; these people included family members, CDS residential support staff, his case manager, his friends Dick and Mary who owned the Malt Shop near the group home, his church minister, and others. Since both Mike and Tim expressed an interest and willingness to live together, the outcome of this meeting was the decision to look for a small residential setting near to the group home, so both men would be able to continue relationships and use of community services and resources in the same neighborhood.

The house is a small bungalow-type structure, situated in a quiet residential neighborhood composed of other similar small and medium sized houses; the houses, which are kept in good condition, are accompanied by small yards to the front and back, often containing a small tree and or some shrubbery and other plantings.

The front door of this house enters into a small living room. There are two couches, a coffee table, one end table, and a large television set, which was purchased by Tim. A staff member told me that when he bought this television he had a lot of money which he had to spend quickly, so he not only purchased this set, but also an identical one for his mother. In one of the windows a plant is hanging; in another window there is a medium-sized fan providing a welcome breeze on this humid summer afternoon. Overall, the room is comfortable, attractive, and adequately furnished, though it seems somewhat bare; the addition of an easy chair in one corner, a larger coffee table, and some additional attractive wall decor would enhance the appearance of this room.

The kitchen/dining area, in the back of the house, contains a small table, a refrigerator and stove, and seemingly sufficient counter top and cabinet space. Back windows from the dining area and kitchen look out onto the back yard, a small grassy plot most of which is overgrown with weeds.

At my request, Mike showed me his bedroom. In the center of the room is a twin-size water bed, covered with an attractive spread in different tones of brown. On top of the bed are two stuffed animals. On shelves and a desk top there are several Special Olympics' trophies. A bulletin board hanging above the desk displays at least 20 Special Olympics' ribbons. Throughout the room, on the walls and the bulletin board, are numerous photographs of Mike and his family members. Mike, who is shy and

not very verbal, did not respond to my questions about his Special Olympics' activities or his family as we looked around his room, but he smiled proudly as he posed at my request beside his ribbons and pictures on the wall.

In contrast, Tim's room is much less personalized. He too has a waterbed, covered with a plain red spread. On the headboard shelf of his bed is one Special Olympics' trophy. His bedside table and two dressers have a few personal possessions on them; one dresser has a stereo set on it.

Similar to the comparison between Lisa and Susan's rooms, observation of Mike and Tim's personal space reveals a contrast between one who has lots of family connections and personalized possessions, and one who has significantly less of these.

Daily life. Mike and Tim get up between 6:30 and 7:00 am during the week to get ready to go to work. Matt, the live-in support staff person, is upstairs in the morning to assist the two men as they prepare for work. Matt commented that morning times were an especially important time for him to be around for Mike since Mike has occasional nocturnal seizures, and thus may be somewhat disoriented and confused in the mornings following these. Mike and Tim leave to catch the city bus to work at about 8:00 am. Although Mike is capable of taking the bus independently, one staff member commented that "it is helpful that he has Tim to travel with, especially after he has a seizure the night before." At this time, also, Matt leaves to go to work from 8:30 to 1:30 as a counselor at a local halfway house for people coming out of jails and prisons. His degree, from the local university, is in rehabilitation counseling, and his

interests seem to be divided between working in the area of developmental disabilities and in criminal justice. Matt, though young, seems to be quite competent and have a high degree of energy.

Tim and Mike both work at Shafer Rehabilitation Center. Currently Tim is working on janitorial skills, but one of his program goals is to learn a variety of different jobs. One problem area noted by his work supervisor is that of hygiene--that is, not showering or wearing dirty clothes to work in the mornings. In addition to this, Tim's work supervisor finds him to be "friendly and outgoing," but to have cyclical variations in his mood and work productivity. Mike works on a contract job for Kodak, assembling videocassette tape boxes.

Mike and Tim return home from work between 3:00 and 4:00 in the afternoon. Matt is also around the house from 3:00 to 6:00 pm to assist with chores and/or meal preparation. On a typical afternoon, Tim might make a shopping list with Matt's assistance, and then walk to the store to get the items on the list, as well as some cigarettes for himself. He spoke about using his personal spending money for his cigarettes, as well as to take his girlfriend, Jean, out to dinner. In the meantime, Matt and Mike might begin preparing dinner.

Matt's hours also include presence in the house from 8:00 pm on through the night. Therefore, from 6:00 to 8:00 in the evening he could "officially" leave and do something on his own. Matt is an avid sports enthusiast, and on evenings and weekends often goes bike riding with Tim or for walks with Mike. It seems as if, in a short period of time, Matt has developed a very

positive relationship with both Tim and Mike, individually. As I walked to the store with Tim to get groceries for dinner, referring to Matt as his counselor, he commented, "I have a good counselor; Matt and I have good talks with each other; we can talk about a lot of things." Later, as Matt and Mike cooked dinner together, there was an easy-going, positive interaction between them throughout the process.

In addition, since the move to this house, either Gwen or Joe, the support people, has been there for a short period of time each day to spend time with Mike and Tim. During Gwen's time with Mike, some of the things they have been working on include his learning use of the telephone and to take his own medicine independently. One of the ways that Joe assists Tim is to meet together once every two weeks with him, his girlfriend Jean, and Jean's staff support person, Gail, to work through issues and problems in Tim and Jean's relationship.

During the week, on Tuesday and Thursday afternoons, Tim goes to a nautilus gym to work out. Also, on Thursdays, he participates in a group counseling and discussion session for people labeled mentally retarded who also have mental health support needs. Both Tim and Mike sometimes take College for Living courses at the local university. In the summers, Mike has been an active participant in Special Olympics--in a variety of sporting events--and has also attended summer camp.

One of the primary social relationships in Tim's life right now is his girlfriend, Jean. Jean, who also has mild developmental disabilities, lives in an apartment with another woman supported by CDS. On weekends, Tim usually stays at her

apartment; on one occasion Jean stayed at Tim and Mike's house. When asked how Jean's roommate, Cindy, felt about Tim staying there, staff members said they thought she "probably liked the extra company around," and that Tim often used his money to take both Jean and Cindy out for dinner. This seems to be a situation that CDS staff members will need to monitor closely with respect to its impact upon Mike, particularly, Jean's staying at Tim and Mike's house, due to his limited ability to verbally express his feelings about this. (Following the site visit, CDS staff reported that Jean is no longer staying at Tim and Mike's house.) Tim told me that he "would like to marry Jean someday," but he's "not sure he things will work out."

Tim also gets together at least once a week with his friend, Phil, who used to live in the same group home as Mike and Tim, but who currently lives in a host home. Often they walk about a mile to Toddy's, a supermarket with a deli/restaurant section, and have a soda there. Also, on Sundays Phil and Tim go to church together; because the busses don't run on Sundays, they get a ride with Phil's parents.

Joe described Tim's parents as having "let go" of him--concerned about him, but not overprotective. He told me that Tim visits them every other week. Mike sees his parents at least once a week. This used to be every Sunday after church for Sunday dinner. However, his father has expressed the need to change this routine so that it doesn't always involve Sundays. So, Mike will now begin to go to his parents house either on

Sundays or on Wednesdays for dinner. Mike also has a brother, Jeff, and sister-in-law and nephew who live in Greeley. He visits them about once every two weeks.

Overall, there are significant differences between Mike and Tim. In term of level of functioning, Tim is much more independent than Mike. Also, in terms of interests, Tim currently focuses time on the development and maintenance of his relationship with Jean, while Mike spends his time outside of work primarily with staff and family as well as involved in sporting activities. Their relationship with one another, while not necessarily a "close" friendship, is characterized by mutual support and concern. These differences do not necessarily mean that Tim and Mike cannot continue to live together compatibly; but, that ongoing attention will need to be devoted to their needs for differing levels and types of staff support.

Sarah

Sarah, who is 27 years old, was institutionalized at birth with severe cerebral palsy. Staff members estimated that her level of mental retardation is mild if any at all, and that most of it would probably be due to her long history of institutional residency. Sarah was able to move out of Grand Junction Regional Center at the same time as Lisa and Susan, through the same arrangement with the state.

Sarah cannot talk intelligibly; when Jay Klein met her in Grand Junction and spoke to her about the possibility of moving and her interest in it, she spelled out on her communication board in response, "Get me the hell out of here." The following

day, when Jay was still at Grand Junction meeting other people, Sarah sought him out again, and told him she wanted three things: "to live with other people with physical disabilities, to have a boyfriend, and to have her own house." By October 1, 1985, Sarah was out of Grand Junction.

Sarah spent the first few months living in a variety of situations: first staying for a week with Lisa and Susan; then living with a woman with physical disabilities. After this, according to Jay, Sarah decided she wanted to live by herself, tried this for awhile and was lonely, so she moved in with a woman who also has physical disabilities for about six months. By this time, I was told, Sarah decided she wanted to live on her own again, and has been doing so since about April 1986.

She is currently living in a housing development called Camelot I, which is a group of about 12 one bedroom brick houses, located in a cluster on a dead-end street, for people with physical disabilities. (There is also a Camelot II at another location in the city.) Staff members of CDS point out that Sarah wanted to live with other people with disabilities, which she is now doing by living here. Yet, they also feel that perhaps at some time in the future Sarah will no longer necessarily want to reside in a place as segregated as Camelot. They are ready and willing to help her obtain an apartment in a more integrated setting.

All of the houses are identical in appearance, front yard lawns are more brown than green, overgrown with weeds in some areas, and the wooden ramps which lead to the front doors of each house are in need of new paint.

Sarah's small house consists of a living room, bedroom, bathroom, dining area, and kitchen. In contrast to the somewhat bleak, deteriorating exterior environment, the inside of her house is well-maintained and brightly decorated. The living room is nicely personalized with interesting, decorative wall hangings, a clock, a colorful afghan on the back of the couch, and two small shelves on the wall with pictures and few few small plants. It seems that it is this personalization which helps makes this house into a home for Sarah.

The kitchen contains a refrigerator, stove, and limited counter and cabinet storage space. Although Sarah can move her wheelchair through this space and would need additional adaptations to use appliances, they are not wheelchair accessible to begin with--something which is surprising in a house that is part of a complex designed for people with physical disabilities. Right outside the kitchen area is a dining area containing a small table with Sarah's "eating machine" on it. This device is activated by two buttons; one starts a handle with a spoon in a circular movement to pick up some food, the other turns the plate of food.

Sarah's bedroom is painted off-white, with red and white curtains in the windows. In addition to her bed, in one corner is a kitchen-type of table with a stereo/radio on top. Shelves above this table hold some records, a few small stuffed animals, and a mug. A lot of clothes are folded on low level shelves in her closet. Neither the bedroom or the bathroom in this house

have doors in the doorways; the hinges are there, and thus the observer assumes that the doors were removed to facilitate Sarah's movement from one room to the next.

In addition to the "eating machine," there are a number of other adaptations that Sarah makes use of daily. In order to utilize these adaptations, she wears a headband around her head, which has attached to it an "arm" which protrudes from the front, with a small rounded tip that is flat on the very end. For instance, the telephone in the living room in equipped with an automatic speed dialing system. Demonstrating for me how this worked, Sarah took half a minute or so to get the "arm" of her headband to the specific button that she wanted to push, and then pushed down on it. The phone also has a speaker system, so there is no receiver that has to be picked up. When Sarah turns on the overhead light in the living room, a radio is also activated. And, as Sarah showed me around her bedroom, she wheeled over to her stereo system and pressed the button that turns on the radio part of this system. I was also told that Sarah has a voice box, but that it is currently in disrepair, will cost about $2,000 to repair, and that her case manager is working on getting it repaired, but is not sure if Medicaid will cover it.

Daily life. Sarah works at the Vocational Center along with Lisa and Susan. On the day I visited, she was sorting nuts and bolts, using the "arm" of her headband to sort the objects in front on her on her wheelchair tray. I was told that Sarah can also use a typewriter and an adding machine, and if the Vocational Center gets funded for a particular grant proposal, they will be able to provide her with training in use of a

'computer. In the long term, however, from the perspective of the staff of this vocational center, physical disabilities seem to present a major barrier to community-based employment. In addition, the philosophy here is based upon the concept of "readiness"--Sarah is not yet ready for community-based employment, but may be at some point in the future.

Sarah gets home from work at about 3:00 in the afternoon. Doug, her primary support person from CDS, spends a few hours every weekday at Sarah's house. Perhaps in his early 30's or so, Doug has been working for CDS for the past two years. I asked what were some of the things he did with Sarah. He told me that she is now participating in her own grocery shopping once a week. He said that this was something that she had always wanted to do, but not been able to before this time. He told me, "We can go down an aisle, and I can ask her do you want this or this, and she can tell me which one she wants." Doug continued by telling me that "she will never be able to do it without assistance," but that she is at least "participating" in it. During part of my visit at Sarah's house, Doug and Sarah sat down to make a shopping list for the next day's trip to the store. This process was time-consuming, and continued for about 20 minutes. Sarah sat next to Doug with her communication board. Sometimes Doug would suggest a specific item and she would agree "yes." Other times, he would ask, "What else do you need?" and Sarah would identify a general area such as "meat," after which Doug would suggest a few types of meat and Sarah would respond to

his suggestions with a "yes" or a "no." Periodically, he would get up to check her refrigerator to let her know what she was getting low on, and what she had a lot of.

Doug also told me that Sarah was going to begin going swimming twice a week with Tracy, a back-up support person for her from CDS. In addition, on weekends, Sarah, her friend Ted, and Lisa go to church services on Saturday evenings (the wheelchair accessible buses do not run on Sundays) and then over to Camelot II to visit with their friends.

Doug explained that on weekends and other times when he is not here, Sarah receives physical assistance and support from staff at this Camelot housing development. However, her case manager had told me that the staff of Camelot don't always provide all of the support that CDS feels Sarah should get. For example, with CDS staff Sarah is working on increasing her ability to tell Camelot aides when she needs a shower, since on their own, the aides don't provide this assistance as often as Sarah would like.

I was curious to ask Sarah about some of the things she liked to do. Her first response to this, on her communication board, was "I like friends." This response surprised me somewhat, in that I had been expecting her to name an activity. It impressed upon me just how important friends are in Sarah's life.

One of Sarah's closest relationships is with Ted, who lives at Camelot and also receives support from CDS. He is about 30 years old, uses a wheelchair, and could probably be characterized as having moderate mental impairment. During my visit to Sarah's

house, Ted was also there with his support person, Beth, for the afternoon. He told me that he usually eats dinner at Sarah's house, although sometimes she comes to his house (which is almost directly across the street) for dinner. They spend almost every afternoon together, as well as much time on weekends. The afternoon of my visit, Ted was calling the Greeley Center for Independent Living to make arrangements for transportation for both of them to attend a picnic being sponsored by this organization. While Sarah has had no family contact since the time of her institutionalization, Ted's mother sees him regularly, and they go shopping together for food which he selects and she cooks and stocks in his freezer.

As we talked about friends, I was reminded that I had been told earlier of a trip Sarah had made independently to Alaska. One staff member wasn't sure who she visited, but suggested that it was a former staff member of an institution she lived in. I commented to Sarah that I had heard she had gone to Alaska. In response, the expression on her face and intonation of her vocalizations indicated excitement and pride about this trip.

Sarah's case manager, Tom, had told me earlier that Sarah has strong ties to Grand Junction, after residing there for so many years, and that she has been back twice to visit friends since October. He said that a friend of hers, who works there, has paid the travel expenses for these visits.

Sarah's future acquisition of further independence and access to more integrated environments will depend to a large extent upon the willingness of support staff (residential, case management, etc.) to creatively explore individualized

adaptations for her. At present, both her primary residential support staff person (Doug) as well as her case manager (Tom) envision further independence and integration--an indication that they will work together with her to achieve this.

Debbie

Debbie is a 54 year old woman who is living in a "living alternative" in Weld County funded through the Medicaid waiver. She has lived at two Regional Centers--Grand Junction and Pueblo--a large 87-person ICF, in two group homes, and in a staff person's home prior to moving into this current setting in April 1986.

Debbie lives with Chris in a lovely two-bedroom house in a residential neighborhood. Chris is a lawyer who conducts the majority of her practice from her home. She has quadriplegia and, therefore, uses a wheelchair and relies on the assistance of aides for help in getting in and out of bed, dressing, and so forth.

According to past reports, Debbie has a history of aggressive behavior including hitting others, throwing things, and becoming verbally abusive. None of this behavior has been evident in this placement. Debbie is totally at home in this house. They have two cats and a dog, with whom Debbie plays and provides care.

During the day, Debbie works at Schafer Rehabilitation Center. After work, she can spend some time alone at home without supervision. At home, Debbie and Chris have a relationship of mutual help. They do a number of household

activities together, such as cooking. Chris provides verbal guidance and Debbie does much of the manual part of meal preparation. If Chris is not home, Debbie will walk the dog when she gets home from work, and can occupy her own time. Support staff are working with her on things such as independent travel, use of the laundromat, banking, and social skills.

According the staff, Debbie has quite a few friends, especially at the workshop. Two days a week she goes swimming or walking with her friend Susan. Finally, the special relationship that has developed between Debbie and Chris is evidenced by the fact that, while Chris is considering moving to California, if she did, she would like Debbie to move with her.

Program Philosophy and Practice

The residential supports that are provided to the individuals described above are based upon both the philosophy and practice of the Residential Support program of Centennial Developmental Services, Inc. Some of these philosophical principles and program practices are described below.

Philosophy

There is a strong clarity of purpose and philosophy originating with the program's leadership and permeating through the entire organization. Components of this include: (1) defining themselves as an agency which provides residential supports to individuals with disabilities in their own homes and apartments, rather than a program which serves clients at program sites; (2) promoting a sense of home; (3) promoting as much

independence as possible for people with developmental disabilities; (4) the belief that all people with disabilities, including those with the most severe disabilities, belong in the community; and (5) promoting an alternative to a continuum-based model of services. Each of these will be discussed in turn below.

Defining themselves. The way this program is defined in language as well as practice is an important aspect of it. Throughout the organization, emphasis is placed upon the provision of residential supports rather than operation of a residential program. Within the CCB, this division is referred to as the "Residential Support" program. On the flyer for this CCB, in 10 words, this program is described as offering, "Living alternatives and residential support in typical environments. Individualized services." In the language of the staff, reference is made to "the people I support," rather than to "clients" being "served." Reference to apartments or homes in which people who are supported by this agency live is to "Sarah's house" or "Lisa and Susan's apartment" rather than use of a street address or program name. Finally, there is an attempt by staff to provide supports to people in an individualized, normative fashion. One staff member commented that the agency is "trying to do things as 'normal' people do, not as programs."

Promoting a sense of home. The Director of the Residential Support program states, "We start with the idea that everybody deserves to live in their own home." Whether or not the lease or ownership is in the person's name (in some cases it is, in other's not), the agency works to promote a sense of

"ownership." This sense of home is reinforced by staff--through the above mentioned reference to people's homes rather than use of street addresses or a program name--as well as by families of people who are supported by CDS--at Mike and Tim's house, Mike's brother, while visiting for dinner, told his 3 year old son, who was playing noisily, to "calm down, this is not your house, it's Uncle Mike's."

Promoting independence/interdependence. The goal of service provision in Weld County is to foster increased independence and interdependence, "with natural supports rather than paid supports." However, the Director emphasizes that the agency will not reduce its supports for a person "without making sure others are there."

When asked how they envisioned the people with disabilities with whom they work in a few years from now, CDS support staff invariably mentioned that they anticipated increased independence. Staff were observed to employ creative, individualized approaches in order to help promote new skills and foster greater independence. For example, one young man with moderate mental retardation who lives with a family is learning to cook with a microwave oven, set his alarm independently at appropriate times on different days of the week, and to take his medicine independently--all through individually tailored strategies which take into account his daily habits, routines, and related abilities.

All people belong in the community. Agency personnel share the belief that all people, including individuals with the most severe and multiple disabilities, can reside in the community.

In order to emphasize this, three people with multiple impairments from Grand Junction Regional Center--all of whom were not on the list for community placement--were selected to be served by CDS in the community. Two now share an apartment, and one is in a house by herself--all three are provided with daily support from CDS staff as well as additional support from other generic service agencies (i.e., visiting nurses). When staff meet weekly to share successes and brainstorm about challenges, discussion is not about whether or not to support a given individual, but rather how best to support that person.

Promoting an alternative to continuum-based services. The Director of the Residential Support program as well as the support staff believe that people should be supported in the community according to their level of need, rather than working their way up through a series of service settings from "more restrictive" to "less restrictive." As an illustration, all three of the individuals who moved out of Grand Junction Regional Center moved directly into shared apartment and house situations.

Program Practices

Small-scale, dispersed settings. CDS has moved toward smaller-scale, more dispersed settings in a few ways. First, it has to "down-sized" or even eliminated some of the larger group homes and assisted people to move into smaller living arrangements. For instance, one group home for seven women was closed and all of the people who lived there are now in one- or two-person supported apartments. A second group home, originally inhabited by eight men, has been reduced to four now. The number

of people living at an agency-owned "4-plex" (four two-bedroom apartments) was eight and has now been reduced to three--the remaining apartment is being rented to nondisabled members of the general public. And, the number of people with disabilities clustered at one apartment complex has been decreased from fourteen to five.

Many of the individuals supported by CDS have long histories of institutionalization; a number of these people have been labeled as "self-abusive" or prone to "violent outbursts." Although the length of time they have been in these small settings supported by CDS is in some cases relatively short, the incidence of these behaviors has been extremely minimal or nonexistent.

Individualized placements and supports. CDS strives to establish residential settings and supports which are as individualized as possible. In the selection of residential settings, the agency attempts to look at where and what type of place would be good for a given individual to live, and with whom, if anybody, rather than fitting people into predetermined residential slots. The Director emphasizes that "we look for good matches as the key" in residential placement. While apartment and house match possibilities are generally initiated by CDS staff, the individuals with disabilities are consulted during the planning process regarding their interest and willingness to live together.

In terms of supports, the Director states that support is provided "based upon need" rather than on funding level. For example, for the "follow-along" level of support, there is a

maximum of 144 hours a year that is covered by funding. However, some individuals receive significantly more hours of staff time. Meg, a 37 year old woman who lives in her own apartment, generally receives about eight hours of support per week; and during a recent "crisis" period in her life she was provided with about 20 hours of support per week.

As need diminishes, or as generic supports are put in place, CDS staff support can be decreased or altered. When Lisa and Susan first moved into their apartment, CDS had a staff apartment across the hall for overnight coverage. However, as Lisa and Susan's degree of independence increased, and visiting nurses began coming in to assist Lisa, this staff apartment was withdrawn.

A strength of the program is the creativity that is utilized by staff in designing individualized supports--in order to assist individuals to attain maximum independence. For instance, one staff person made tapes of music and messages to assist an individual in getting through her morning routine. In addition, supports are flexible, and can change according to individual need or request. For example, as described previously, Jan had been coming to see Lisa once a week for three hours to work on money management skills. However, Lisa requested that she come one other day of the week, more for a social visit. So, Jan altered her schedule, and now comes on one day for about two hours to work on money management and on another day for about an hour for a social visit with Lisa.

Individualized, flexible "programming" in natural contexts. Formal programming for people who are supported by CDS is highly integrated into normal, daily living routines. Emphasis, in the language of the staff, is not placed on this programming as a "program" or "therapy"; rather, it is considered part of the daily activity of life. When Susan and Debbie exercise together, this is referred to as their "going swimming" or "going for a walk" rather than as an "exercise program." For purposes of Division funding, staff must document progress on certain program goals for some individuals; however, the charting or documentation is inconspicuous to the casual observer or visitor. In addition, programming is flexible, and not forced, and can be reevaluated and/or redesigned according to a person's needs and abilities.

A strategy of "partial participation" or "interdependence" is utilized, providing the opportunity for even the most severely disabled individuals to learn new skills and participate in daily living activities and routines. In addition to the example of Sarah's participation in grocery shopping, she and others who cannot write participate in banking by stamping their own checks.

With respect to behavior management, according to the Director, the agency employs no formal "behavior programming." Rather, behavioral issues are dealt with as they arise, using as natural, normative consequences as possible. For example, instead of instituting a special "time-out" program, one staff member spoke of how when the individual she is with is in a bad mood, "I'll just go for a walk, or go do something else for awhile so she's not getting my attention."

Staff relationships with each other and the people they support. A strong aspect of the Residential Support program in Weld County is the relationships that have developed between staff. Staff work in team of four to provide support to the individuals with disabilities. An atmosphere of "team" work is further nurtured through the weekly "team meetings" of the entire residential staff. There is a pervasive attitude that they are all working together toward common goals. Staff openly share with one another and the director problems or dilemmas they face, and ask for help in solving these problems.

This is a somewhat unique situation in that all of the staff know a great deal about all of the people who are supported by the program. When issues are raised, either informally or at staff meetings, staff members are able to give each other feedback based on their knowledge of the person through staff meetings or their own experience with this person. Staff readily provide coverage for one another for time off. In fact, one staff member commented that if you took time off, but stayed in town, you might well end up working anyway. She advised, "If you want a vacation, you have to leave town."

Without exception, the relationships that have developed between the community support specialists and the people they support are exemplary. There is evidence of a great deal of warmth, trust, and mutual acceptance between staff and the individuals whom they support. The people with disabilities who were verbal talked openly and clearly about the staff, about what was expected by the staff from them, and about what type of support was available to them and from whom.

Staff attitudes toward the people they support are extremely positive. This is reflected both in their interactions with these people, as well as the way they talk or think about them. Staff invariably believe that the individuals they work with can acquire more skills and more independence, and work to foster and encourage this in the context of their relationships with the person. There was never a question raised about anyone's ability to continue to live in a residence that was supported by the program. The only questions ever raised involved ways in which people might need to be supported.

In many cases, staff have involved the individuals with disabilities whom they support in relationships with their own families--taking them to family homes for visits, inviting them to family parties and picnics, and bringing their children in to visit people in their apartments or homes.

Staff members see themselves as "models" for the people they support, and seem to be acutely aware of the need to present the most positive image they can, both for the sake of the people they are supporting and for the community. Staff also view establishing community relationships as part of their role and responsibility. They therefore make efforts, both with and on behalf of the people they are supporting, to get to know neighbors, to become known in local establishments, and so forth.

Conclusion

In Weld County, some individuals, including those with severe and multiple disabilities, and others with challenging behaviors, are being provided individualized residential

supports. This does not mean that supports and community integration are at an ideal level. Problems and difficulties still exist. For some individuals, there has been significant movement from one residential setting to another, disrupting the potential to establish strong localized community connections and relationships in neighborhoods. Some individuals have a great deal of daily and weekly experience and activity in integrated community settings--yet, almost all of this is with staff, family members, or other people with disabilities. In some cases, therefore, further effort could be directed to helping individuals with disabilities establish long-term social relationships with nondisabled people other than staff and family. In addition, more staff assistance could be provided to some individuals to achieve greater personalization of their living environments, or to help remedy situations in which people are either living in places which are exceedingly dirty or have poor personal hygiene practices. Such issues are challenging to any agency--to both encourage people with disabilities to express personal options and preferences, and at the same time assist them to live in ways that enhance rather than detract from their potential social integration into the surrounding neighborhood and community. While staff at CDS have not come up with all of the solutions to these problems, there is a strong willingness to openly deal with these issues and to accept the responsibility for figuring out how best to support each individual.

The residential support situations described in detail in this paper are all relatively recently established. Lisa and Susan have been at their apartment now for just over a year; Mike

and Tim have been in their house for about a half a year; Sarah has been in her home for just over a year; and Debbie has been living with Chris now for close to a year. For Weld County to continue to support these individuals as they are now supported, and to support others like them, a few factors play an important role.

First, in Weld County, there are numerous examples of individuals receiving services and accruing expenses that are unrelated to their source of funding. Because of some creativity on the part of the CCB in pooling funding sources and using flexibility in residential supports--providing supports where needed, withdrawing or decreasing them where no longer necessary--the program has been able to remain solvent in spite of the funding categories of the state. The new "personal care alternatives" funding category, however, should help alleviate this problem and facilitate the creation of further individualized supports.

Second, because there are only 67 people supported by the program, the staff and administration can stay informed and personally involved with all of the residents of the program. They are aware that they will lose this if the program grows much larger, and therefore are committed to keeping the program small. They have a track record of success and a willingness to accept people who present significant challenges behaviorally, medically, and physically. Their ability to continue to provide supports as they have been will depend upon their ability to stay small.

Currently, however, CDS is providing individualized residential supports to people such as Lisa, Susan, Tim, Mike, Sarah, and Debbie--a support that is characterized by both creativity and commitment on the part of support staff; and a support that results in individualized options, and the opportunity to express and exercise preferences and choices for the individuals who are supported by this program. This has been made possible through both the agency philosophy and practice described above.

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